

MINUTES OF THE
JOINT HEALTH AND HUMAN SERVICES APPROPRIATION SUBCOMMITTEE
Friday, January 31, 2003, 2:00 p.m.
Room 131 State Capitol

Members Present: Sen. David H. Steele, Committee Co-Chair
Rep. Jack A. Seitz, Committee Co-Chair
Sen. Paula Julander
Rep. J. Stuart Adams
Rep. Calvin G. Bird
Rep. David Litvack
Rep. Rebecca Lockhart
Rep. Roz McGee
Rep. Mike Thompson

Members Excused: Sen. Leonard Blackham

Staff Present: Spencer C. Pratt, Legislative Fiscal Analyst
Thor Nilsen, Legislative Fiscal Analyst
Norda Shepard, Secretary

Public Speakers Present: Karman Senone, Salt Lake County Aging Services
Rick Kinnersley, President, Utah Hospital and Health Systems Association
Tina Johnson, Chairman, Legislative Coalition for People with Disabilities
Krysti Dabb
Stephanie Carlson
Drew Hyde, President, AurorA Mental Health Project
Sylvia Garcia Richard, Utah Breast Cancer Network
Wayne W. Cottom, Dental Director, Community Health Centers Inc.
Deana Lee
Miriam Hyde, Associate Director, AurorA Mental Health Project
Judi Hillman, Health Care Policy Analyst, Utah Issues
Glee Ann Clayton, Legislative Coalition for People with Disabilities
Bobbie Wickens
Anna Topham
Mary Ann Strong
Darla Murphy
Dixie Berg, Director of Training, Alliance House
Margie Mathera, Member Alliance House
Andrew Bell
Ryan Herron
Nancy Nelson
Diana Blaylock
Beverly May
Tamara Lewis, Chairman, Community Advisory Board for Tobacco Prevention
Diane Whittaker
Russell Charles Barry
Keith Nelson
Corey Rolley
Barbara Toomer, Disabled Rights Action Committee
Sheila McDonald
Dan Smith, Disabled Rights Action Committee

Ricki Landers
Ken Wulle, Disabled Rights Action Committee
Lopeti S. Penima'ani
Dawnita Logary
Kenneth Robertson, Utah Independent Living
Joy Poncelow
Joan M. Gallegos, Executive Director, Utah Health Care Association
Bill Peterson, President, Utah Health Care Association
Elizabeth Jensen
Kevin Morris
Gregory Jones, Chairman, Medical Care Advisory Committee
Karen Wildfoerster
Don Pace
Mark Anderson
Norm Swaton
John Pally, Executive Director, Alliance House
Nedra Taylor

List of Visitors on File

Meeting was called to order by Co-Chair Seitz at 2:02 p.m.

Co-Chair Seitz announced that the meeting would be set aside for public input on the Department of Health. He said we would probably not get through the complete list of those who wished to speak because of time. He asked those speaking to limit their time to two minutes.

Karman Senone, Salt Lake County Aging Services, said she was speaking as a voice for the frail and vulnerable elderly with a serious concern regarding the proposed reduction in Medicare eligibility from 100% of poverty to 75% of poverty. She said the health department estimates this reduction would affect approximately 6000 individuals. She distributed a handout to committee members voicing this and other concerns.

Rick Kinnersley, President, Utah Hospital and Health Systems Association, stated he understands that this is one of the worst years the state has seen in terms of the economy and the problems with which the committee is dealing. He distributed a handout outlining the economic consequences of a reduction of \$30 million of state funding to the Medicaid program, which would transfer into a \$100 million reduction to the medical community and to those who depend on the Medicaid program for life sustaining matters. He said he wanted to remind committee members that when cuts are made to providers, the consequences are predictable. Providers will reach a point where they will not take Medicaid patients or will limit their practice. Hospitals are different in that by law they have to provide care to everyone who comes through their doors whether they can pay or not. When hospital payments are cut, those reductions will find their way in a form of a hidden tax to the business community.

Tina Johnson, Chairman, Legislative Coalition for People with Disabilities, thanked the committee for the time allowed for these expressions of concern. She also thanked Michael Deily for all the work and concern he has shown in trying to extend the Medicaid budget. She used a Mr. Potato Head toy to demonstrate the programs that have been lost: vision, dental, audiology and therapy. She said this has the potential to incur greater Medicaid cost through emergency room visits, institutional placement and hospitalization. She distributed three handouts concerning audiology, HHS press release and information on the Medicaid Work Incentive Program

Krysti Dabb stated she was here to speak as an advocate for audiology and hearing services and how this service had

impacted her life. She said without these services she wouldn't be able to speak today. She explained that she was born deaf and with these services she has had speech and audiology therapy and is now able to talk and communicate with people. She said without these services people like her would find it difficult to find employment, be aware of their surrounding for safety measures or have the ability to communicate efficiently with others.

Stephanie Carlson showed a picture of her son, Travis. She said they had been fighting for eleven years to keep him at home, but three weeks ago he had to be placed in an institution to get the help that he needs because of the cuts and changes in IDCA access and the HMOs, who are pulling out of the program. She said it had come to the point with these cuts that the family could no longer care for him at home. She stated any further cuts will be that last straw for many people. She said her family cannot get medical insurance because of Travis. She stated her request was not to fund something that has never been there, but to seriously consider what is cut because every cut will have a massive impact.

Drew Hyde, President, AurorA Mental Health Project, distributed a handout. He stated he wished to address the Medicaid work incentive program. He said the right to work is a basic civil right and people with disabilities want to work. People with disabilities are capable of working. He stated there are structural problems in our current systems that punish people with disabilities when they do work. He stated these problems violate basic civil rights and would not be acceptable for any other group in our society. He said the 2001 Utah State Legislature and Governor Leavitt committed to changing the oppressive part of the system and he urged a continuation of this commitment.

Sylvia Garcia Rickard, Utah Breast Cancer Network, distributed a letter and explained that two years ago one time funding was funded for the Medicaid Optional Breast and Cervical Cancer Treatment Program, and last year the funding was moved to on going funding. She said this is an incredible effort to save the lives of women who have no insurance and no means of paying for the treatment they need. She said many lives have been saved because of this program. She said she comes now during these rough times to ask for continued funding for this life saving program.

Rep. Litvack stated that he would like to make everyone aware that recently Sylvia has been awarded the Cesar Chavez Peace Award for her efforts as an advocate in health care with the Hispanic people. He congratulated her and stated her efforts were deeply appreciated. He said this was a tribute to what she has done, but also a tribute to all the people who are advocates.

Wayne W. Cottom, DMD, MS, Dental Director, Community Health Centers Inc., distributed a handout and stated he wanted to talk about one item. He stated that dental services are critical to maintain, employability, health, nutrition and self esteem. He stated that surveys have found that dental services are the most difficult health services to obtain for low income people. He stated the \$17 million would provide Medicaid adults, including developmentally disabled and those in long term care facilities, with the same level of benefits as those adults on the Primary Care Network and Medicaid children.

Deana Lee explained that she had an injury in 1990 and expressed what the dental program had done for her. She said her teeth have become worse and the benefits have been cut. It affects her overall health. She said she felt it is important to restore dental coverage, even at a basic level.

Miriam Hyde, Associate Director, AurorA Mental Health Project, explained that both she and her husband have bipolar disorder. She stated it is understandable that cuts have to be made to the state budget, but making cuts to the most vulnerable population, the elderly and the disabled, is unconscionable. She said the cuts will affect her personally. She said even though she will soon be eligible for Medicare, it will not cover prescriptions and she and her husband's combined prescriptions bill is over \$2000 a month. She said she and other members of Alliance House all have the same plea, to not take away the medications that keep them sane and stable. She also stated that if you cut the Medicaid buy-in program which allows people with disabilities to work and maintain their medical benefits, you are taking away any incentive to work.

Judi Hillman, Health Care Policy Analyst, Utah Issues, distributed a packet called "Utah Medicaid Matters" which

outlines the human and fiscal impacts of medicaid cuts and restorations. She said many individuals and organizations have been breaking their backs to make the case to protect Medicaid. These advocates have been wondering how many ideas, how many revenue sources and how many stories should be given to the committee to adequately present the need. She displayed a back pack which she said was full of stories that have been sent to her. She said we are talking about the difference between walking or using a wheel chair, living at home or in an institution, and sometimes life and death. She said the packet contains some recommended revenue alternatives to cuts and other pertinent information.

Glee Ann Clayton, Legislation Coalition for People with Disabilities, said she works with children's special health care needs. She distributed a book containing a collection of over 300 stories from families in the early intervention program. It also contains a fact sheet on early intervention. She said she is also a mother of three children, two of whom have special needs so she has first hand knowledge of the value of early intervention. She said early intervention brings hope for all families that no child will be left behind.

Bobbie Wickens introduced her daughter Isabel and said she was a living miracle as a result of early intervention. She explained that because of early intervention she was empowered as a mother with knowledge to help her child. She said we all know the benefits of addressing problems when these children are young. She asked the committee to reassess and have funding continue for early intervention. She said it is not about money, it is not about power, it is not about budget costs, it is about people, her daughter and all these children who have come into the world with disabilities. She said we need to take care of them and empower them so they can be functioning adults.

Anna Topham explained that her 18 month old twin boys are participants in the DVI Advantage Early Intervention Program. She said the twins were born early and have experienced mild to moderate developmental delays in several areas. She said through the care and expertise of the Early Intervention therapist the boys have made great progress. They are all but caught up in all areas except for language areas, where they are continuing to receive therapy. She stated she wanted to impress the main point that children with moderate to mild problems don't always get access to health care systems and Early Intervention may be the only help available to them.

Mary Ann Strong showed pictures of her two adopted daughters. She expressed how grateful she is for the great therapist from Early Intervention who is helping her one daughter learn to speak, who noticed her need for glasses, and other things that will help her to soon be on age level developmentally. She said the great technicians at Early Intervention have helped her as a mother to learn how to help her children. She said the savings to the school district because of Early Intervention cannot be imagined. She stated it is estimated that every \$1 spent in Early Intervention saves \$6 down the road.

Darla Murphy said she is a mother who can testify to the benefits of Early Intervention. She said she has three children, two who have been in Early Intervention. She said when her son, D.J., started preschool, his teacher thought he was a behavioral problem. This was a shock to her because he was well behaved at home. The preschool had a speech pathologist who discovered that D.J. was trying to communicate but because of poor speech was not being understood by others. She said that if funding was restricted to only severe cases, her son would not have qualified. He could have slipped through the cracks and continued to be a behavioral problem. He had speech therapy and is doing much better. She said there are many benefits in treating problems early. Her younger son, William, has been having speech therapy since he was two and is making great improvement. She stated she can't begin to tell the difference this program has made.

Rep. McGee stated she wished to thank the parents who have made the effort to come and share their experiences with the committee and for providing information from those who could not be here. She said she was impressed with the respectful way in which this program is providing services to the parents in the homes of these children.

Dixie Berg, Director of Training, Alliance House, stated she has been working with adults on disability and Medicaid for over eight years in a model that promotes work as a vehicle towards recovery. She said over the years she has seen numerous people regain hope, confidence, and self respect through returning to work in the community.

She said the proposed cuts will make it impossible for a large number of people throughout Utah to even take the steps to move on because it would be financially devastating. It will also cause many who are currently working to quit their jobs. These people want to make a positive contribution to society and get on with their lives. They need to be able to see themselves beyond their disabilities. She asked how can it be beneficial to cause someone to stop working.

Margie Mathera, a member of Alliance House, said she was very concerned about the cuts and the proposed cuts in Medicaid, especially for the handicapped and mentally ill. She explained it would be a strong burden as medications would cost nearly \$1837 and if they could not pay for them, they would end up in the hospital. She asked that those considering action consider all positions of the mentally ill and the handicapped. She distributed a letter.

Andrew Bell said he would like to thank everyone for this opportunity. He said his mother wanted to be here today but she is nearly bed ridden. He said most of his life his parents have needed medication and his mother has been in a wheelchair. He said it is a steep slope every day for his family to climb and if cuts are made it will be added weight to their shoulders to carry up those hills.

Ryan Herron stated that his only income is a monthly SSDA check of \$748 and he has Medicaid. If the proposed cuts are made he will have to spend down that amount to \$383 to keep Medicaid. He stated he would prefer to go to work and has had recent employment successes. He said without his medication he becomes depressed and suicidal and ends up in the hospital, costing the state more money. He says all he wants to do is become better and be able to work. He distributed a letter.

Nancy Nelson stated she worked for the health department for 17 years and then had a mental breakdown. She said she needs medications and can't pay for them and can't believe she will be penalized if she goes to work. She asked that funding be seriously considered because the problem is serious.

Diana Blaylock stated that in 1983 she was diagnosed with bi-polar schizo-effective disorder and it took many years and different medications until the right medications were found for her. She said she is finally able to work, but if the proposed cuts are made she will no longer be able to work. She stated that without her medications she becomes a threat to the community and herself. She said she would more than likely be hospitalized or in a nursing home and not be able to pay taxes and be a normal member of society.

Beverly May spoke on behalf of Campaign for Tobacco Kids. She said Utah's efforts to reduce tobacco use are paying off. She stated that compared to 1999, fewer students and fewer adults smoke and more smokers want to quit, but it is critical that there be a sustained funding to maintain this success. She said if people call the Quit Line they are able to get help and if they have the help to stop smoking, it saves money for the state. She said they were not asking for more money but they want to maintain the funding that is currently there.

Tamara Lewis, Chairman, Community Advisory Board for Tobacco Prevention Program at the Department of Health, said that \$81 million is going toward the medical costs of Medicaid patients for conditions directly caused by tobacco use. At the same time, the tobacco industry is spending \$65 million in our state in aggressively marketing their products to low income and vulnerable populations. She stated the dollars appropriated to tobacco control have been invested very carefully in the most effective programs available. The Utah Tobacco Quit Line has been especially successful.

Diane Whittaker stated she was born mentally ill and was started on medications at 3 years old. She said if she does not have her medications she would be confined to the state hospital. She stated she would be very distraught if she did not have her medications.

Russell Charles Barry, stated he has been helping mentally ill people for a very long time. He said he is taking about \$2000 worth of medication a month and it would be difficult for him to afford this without Medicaid benefits. He said he hoped the benefits won't be cut.

Keith Nelson stated he loves America and is very grateful for the care this country gives him. He read a letter stating that it is very sad that 20% of the population is homeless when 10% controls 90% of the wealth. He said many of the homeless suffer from schizophrenia. He stated the disease is genetic in nature and is a result of a chemical imbalance in the brain. He said he felt it would be very cowardly of our government to take away Medicaid funds for medications. He said this would not save money in the long run.

Corey Rolley, spoke representing the Utah Statewide Independent Living Council. She said that in 2001 during the general session, the council worked together with members of the Governor's office, the Legislature, Medicaid, and The Division of People with Disabilities to find answers to help people go to work and move toward going off of cash benefits. Many of the people who were on Medicaid would lose their health care coverage if they earned too much money. The message became that if you needed health care, don't work. She said a program was worked out called the Medicaid buy-in that enabled people to go to work to support their families. The system worked and many people trusted the program and went to work. She stated that now with the proposed reductions, the buy-in payment has gone from 35% to 55% of people's income, which results in people having to quit their jobs in order to go back on the Medicaid rolls. She said we have to support people on work rolls.

Barbara Toomer, Disabled Rights Action Committee, distributed a letter and an outline of suggestions for promoting independence. She stated she was here to tell the committee how to save the state money. She stated her committee has a project called "Our Homes, Not Nursing Homes," and it has helped over 50 people get out of nursing homes into a more integrated setting. She said the way the Legislature can accomplish getting people out of nursing homes is by endorsing the cost-neutral Legislative Intent Language offered by Rep. David L. Hogue that will be coming before the subcommittee. The language states that as individuals relocate from nursing home facilities to community care services, their funds will transfer with them into the community. She asked for support for this intent language.

Sheila McDonald stated she is a health care advocate with the Salt Lake Community Action Program. She said they serve about 1500 low income families a year. She said the proposed Medicaid cuts will hurt very vulnerable populations, undermine our health care system for everyone, increase emergency room crowding, increase the burden of uncompensated care, and reduce the number of health care givers. She said Utah should take advantage of Utah's favorable match rate to bring in all the federal match possible. She encouraged support of S.B. 82, support of the moratorium on tobacco funds and ask committee member to speak boldly to have those funds earmarked for Medicaid, and support a preferred drug list.

Dan Smith stated he is a volunteer with the Disabled Rights Action Committee which helps to get people out of nursing homes and back into the community. He stated he had lived in a nursing home and could not stand it. He asked for support of the resolution mentioned by Barbara Toomer. He said it is much more costly to live in a nursing home than out in the community.

Ricki Landers distributed a letter. She said she was speaking on behalf of herself and many, many other disabled people in the community. She stated she has been disabled with MS for about 18 years. She described the effects of this disease. She said she has a great need for physical therapy in order to keep going and be a part of the community. She said the cuts in Medicaid services, community based services and increased co-pays is no laughing matter and many people will have to decide which they can painfully live without, food or medication, groceries or freezing, freezing or getting the much needed medical care or physical therapy they require.

Ken Wulle, a volunteer for the Disabled Rights Action Committee, stated that much of the work he does involves assisting individuals in nursing homes gain access to homes in the community. He said it is more economical for the state to subsidize these individuals within their own apartments or homes with attendant services than to continue their existence in nursing homes. He stated the nursing home industry seems to think they have a claim on our disabled population. He said disabled people do not give up their rights to life, liberty and the pursuit of happiness when they lose their ability to walk or are otherwise disabled.

Lopeti S. Penima'ani, distributed a letter and stated he has had to face many medical challenges over the last 10 years. He said he suffers with an extreme case of Fibromyalgia, Lymphedema, and Tropical Spastic Paraparesis, all of which cause chronic pain and are debilitating. He stated he worked for years but as his medical condition worsened he came to the realization that he had to accept help from others. He indicated he must spend down nearly 2/3 of his income to qualify for Medicaid benefits, which doesn't leave much left to pay rent or for specialized transportation costs. He stated that physical therapy is a very important part of his medical treatment.

Dawnita Logary, stated she is 44 years old and on disability. She stated she was injured in a car accident in 1974 that put her in a wheelchair and she has had to depend on the state for all of these years, but wishes she didn't have to. She said if the Medicaid waiver program is taken away she will lose her care giver and be put into a nursing home. She said she had been in a nursing home before and does not want to return because it takes all of her freedom away.

Kenneth Robertson stated he is a proud tax payer and works for Utah Independent Living and has fought for 30 plus years for independence for all or better yet, inter-independence, as we all rely on someone else. He urged that funding not be cut for hearing aids, dental care, and physical therapy. He stated that disabled people want to give back to the community. He said to please save us so we can prosper.

Joy Poncelow stated that her husband, Rick, are both on Social Security Disability and her husband has a terminal illness. She said their income is \$1184 a month and Medicaid wants them to spend down to \$688 a month. She stated they cannot afford that and their only option is to divorce so her husband can have his needed medications to stay alive. She said she hoped some way can be found to help them and others faced with the new spend down payments.

Joan M. Gallegos, Executive Director, Utah Health Care Association, distributed a prepared sheet. She said she wanted to go on record to support the RUGS program because it is working. She said there are ways to stabilize funding for the Medicaid program. She stated that Gordon Crabtree's presentation on 1-27-03 has considerable merit and needs further attention. She said other suggestions are to change the tobacco settlement allocation amounts and to continue working actively with providers to identify ways to save Medicaid dollars. She said she has hope because Utah has a tradition of working things out.

Bill Peterson, President, Utah Health Care Association, thanked the committee for their concern, support and interest in the elderly. He stated that if the association can be of any further service it is more than willing to help.

Elizabeth Jensen stated she works part time in the Whitmore County Library and at Alliance House. She said she suffers from a mental illness. She stated she wants to continue to work. She feels better and has greater self esteem when working, but in order to do this she needs her medications. She stated that with the proposed cuts she would probably have to quit working in order to qualify for her medications.

Kevin Morris stated he worked with the Provision of Early Intervention Services to families in Salt Lake, Tooele and Duchesne counties. He stated the growing need of these services demands not a waning but an increased commitment. He said they are positioned to provide help at the most critical time. He said any problem addressed early is much better than later or not at all. He stated they are required to serve all who qualify and they are committed both to the law and the principle but funding needs to be found.

Gregory Jones, Chairman, Medical Care Advisory Committee, distributed a letter. He stated the role of his committee has been very frustrating the past few years. He stated that during times of low economy, there are more people who need care. He stated he would like to remind the committee of three important aspects of the Medicaid Program: (1) The human side which allows recipients to receive basic care and without Medicaid programs many of the recipients suffer enormous loss in their quality of life, (2) The medical side which provides vital medical services, many of which can be life threatening and need immediate attention and (3) The financial side where the

state receives almost three dollars from the federal match program for every dollar spent. We need to leverage these federal dollars. He stated we cannot wait for a better economy.

Karen Wildfoerster, stated she works for Alliance House and spends nearly every day with individuals with mental illness. She says they are some of the most wonderful people she has ever met and some of the most vulnerable. She said that though many of the things the committee has heard today about making choices between food and medicine may seem to be cliché, please know these are the real lives of these people. She said if the proposed reductions are made, the cost will be greater than the savings.

Don Pace said he appreciated the opportunity to testify. He stated he feels there is a gross injustice being done to married senior people, or even married people in general. He asked that why, in a state that believes in the sanctity of marriage, are people told that if they were single they could be helped, but since you are married we cannot help you. He said something needs to be done to change this inequity. He said he wants medical help for his wife without having to divorce.

Mark Anderson, a physical therapist, asked the committee members to stand for a minute. He stated this was a little bit of therapy and people are needed to “stand up” for physical therapy for the Medicaid recipients of Utah. He stated physical and occupational therapy are services that help to improve a person’s independence and ability to function to provide activities of daily living. He said it is a great concern that these services are not going to be available to help these people become more independent.

Norm Swaton stated he is the father of three special need boys. He said they have been informed that their physical, occupational, speech, and feeding therapy benefits have been cut. He said he supports moderate taxes to pay for life sustaining service. He asked the committee to support legislation that keeps the basic quality of life at a reasonable level.

MOTION: Rep. Lockhart moved to approve the minutes of 1-29-03 with one correction. The motion passed unanimously.

MOTION: Rep. Litvack moved to adjourn. The motion passed unanimously.

Co-Chair Steele adjourned the meeting at 5:00 p.m.

Minutes reported by Norda Shepard, Secretary.

Sen. David H. Steele
Committee Co-Chair

Rep. Jack A. Seitz
Committee Co-Chair